WS2.1 "Feeling my way": Information needs for parents whose child has been diagnosed with CF following newborn screening

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Objectives: To investigate education needs and information seeking behaviours of parents whose infant is diagnosed with CF. Initial diagnosis and education are landmark events for parents whose child has CF. Education delivery and content exert powerful influences on parental adjustment to diagnosis and ongoing engagement with the CF team. Despite the introduction of NBS over 20 years ago in Australia, there is a dearth of studies investigating education needs of parents during this pivotal period. Even with good intentions, current practices may fail to meet parents' information and care needs.
Method: In depth interviews were conducted with parents (N = 10) of an infant aged from 1 to 3 years diagnosed with CF following NBS. Thematic analysis revealed a sense of parents being overwhelmed with too much startling information too soon for some; and a desire for education delivery at intervals over the first year. Most wanted more pragmatic information about aspects of treatment and disease they could modify/influence, and the impact of infection control measures on lifestyle. Many perceived their independent search for information a negative experience. Participants offered constructive insight into factors affecting their engagement with the process, and recommendations for more appropriate context, content, format and timing of delivery.
Conclusion: Insight into education content and delivery, optimal timing and environment for this initial period of diagnosis and education from a parental perspective is requisite so that relevant, accurate education can be developed and provided in a format (such as web-based materials) that is readily accessed by parents.

WS2.2 What do parents experience and how do they cope with the AREST CF early surveillance program for infants and children with cystic fibrosis?

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Background: The Australian Early Surveillance Team for Cystic Fibrosis (AREST CF) runs a unique clinical early pulmonary surveillance program (EPSP) for preschool children and infants with CF from diagnosis following NBS. Children undergo annual bronchoscopy and CT scan thorax under general anaesthetic to detect signs of early lung disease. Parental experiences of their child's engagement in this program remain largely unknown and warrant exploration.
Aim: To explore and report the range of psychosocial experiences of parents whose children are enrolled in the EPSP and to characterise coping styles and strategies.
Methods: A qualitative research design of semi-structured interviews for parents of children with CF. Parents were randomly selected from the purposive sample of patients attending Perth CF Clinic. 16 parents (5 fathers, 11 mothers) of children aged 1–6 years (M = 3 years) participated. Items explored emotional, social and family experiences related to the annual surveillance program. Thematic analysis identified common experiences and emergent themes.
Results: Dominant themes included anxiety and fearfulness regarding the surveillance procedures, the perceived risks associated with these and anticipated distress of their child. Coping strategies included distraction, denial and cognitive reframing. Most perceived the EPSP as beneficial for their child's future. Understanding and prior experience of procedures and the reasons for them aided parental coping.
Conclusions: This is the first study of how parents experience and cope with the EPSP and data will inform design and implementation of psychosocial supports for families within the EPSP.

WS2.3 Parents' roles and involvement in young adults' clinic appointments

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Objectives: To describe young adults' views and preferences regarding their parents' roles and involvement in clinic appointments in adult health settings, and parents' explanations of their level of involvement.
Methods: Qualitative, semi-structured interviews with 34 young adults (aged 17–25 yrs) with childhood diagnosed chronic conditions including cystic fibrosis (n = 12), muscular dystrophies and renal disease, and 19 parents (recruited via young adult participants).
Conclusion: Independence in other areas of the young adults' lives did not predict a lack of parental involvement in appointments. Parents assumed similar roles to other 'companions' accompanying patients to clinic, namely: communicator, information receiver and emotional support. Young adults wanted parents to attend appointments with them, either routinely, or when difficult information/significant decisions were expected, or the young adult was struggling to communicate with the team. They valued being able to 'recall' their parents to being involved in consultations. Parents not attending were often involved in priming, de-briefing and/or providing emotional support. Parents who remained highly involved in appointments explained this in terms of the young adult's lack of maturity and/or understanding of their condition and its treatment regime. The life-threatening nature of the condition meant some believed not attending appointments was too risky. Companions are typically viewed positively by health professionals yet a parent's presence in adult clinics can be problematised. The findings reported suggest the rationale for taking this different view may be simplistic and requires further scrutiny.

WS2.4 Use of non-prescribed medicines, supplements and therapies by children with cystic fibrosis, other chronic illnesses and children with an acute injury – A comparative mixed-methods study

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Aims:
– To quantify, describe and compare non-prescribed agent (NPA) use by children with cystic fibrosis (CF), other chronic illness and no chronic illness
– To explore families' motivations for giving (or not giving) NPAs.

Methods: A questionnaire and semi-structured interview study using an explanatory sequential approach recruiting parents of children attending CF, haemato-oncology, neurology, development and fracture clinics, Oct-Dec 2011. Quantitative data were analysed using descriptive statistics, chi-squared and multivariate analysis. Qualitative data, collected from interviews until data saturation, were coded and thematically analysed by three independent researchers.
Results: 295 questionnaires were completed, 44 children had CF (14.9%). Response rate-44.4%, 60.3% male, mean age 9.2 years. Prevalence of NPA use was 37.3% overall (CF = 34.1%). Specific prevalences – 10% fish oils, 16% vitamins, 15% probiotics, less commonly noted included homeopathy and hyperbaric oxygen. Differences in NPA use between clinics were not significant ($p = 0.21$). NPA use was not associated with age, gender or socioeconomic status. Sixteen parents completed interviews (3 CF). Ten themes were identified. Those describing why parents provided NPAs included a wish to take an active role, trust (in health professionals, or remedy of choice) and accessibility of doctors/NPAs.
Conclusions: This is the first UK-based study to compare NPA use between children with CF, other chronic illness and no chronic illness. Children with CF were no more likely to take NPA's than other children. Parental motivators are complex, relate to intent, trust, and a wish to take an active role in their child's healthcare.